Section 3, Part C: Partner Counseling and Referral Services (PCRS)

PROCEDURAL GUIDANCE FOR IMPLEMENTATION OF PARTNER COUNSELING AND REFERRAL SERVICES

CBO PROGRAM ANNOUNCEMENT RFP 04064
DEPARTMENT OF HEALTH AND HUMAN SERVICES

DESCRIPTION OF PARTNER COUNSELING AND REFERRAL SERVICES

Evidence suggests that most new HIV infections originate from HIV-infected persons not yet aware of their infection. This finding emphasizes the need to identify HIV-infected persons and link them to medical, prevention, and other services as soon as possible after they become infected. One strategy for accomplishing this is voluntary partner counseling and referral services (PCRS), including partner notification. In most jurisdictions, state and/or local health departments are legally responsible for ensuring the public health through the control of infectious diseases. PCRS is a strategy that most health departments use to achieve this goal. For this reason, CBOs who wish to provide PCRS are required to collaborate with their state and/or local health departments.

PCRS is one of a number of public health strategies to control and prevent the spread of HIV and STDs. PCRS assists HIV-infected persons with notifying their partners of exposure to HIV. A key element of PCRS is informing current and past partners that a person who is HIV-infected has identified them as a sex or injection-drug-paraphernalia-sharing partner and advising them to have HIV counseling and testing. Notified partners, who may not have suspected their risk, can then choose whether to be tested for HIV. Those who choose to be tested and are found to be HIV positive can receive early medical evaluation, treatment, and prevention services, including risk reduction counseling and PCRS. Sex and injection-drug-paraphernalia-sharing partners might already be HIV-infected but be unaware of or deny their risks or their HIV status. PCRS provides an opportunity for HIV primary prevention interventions for those partners not infected with HIV and an opportunity for primary and secondary prevention for those partners living with HIV. Informing partners of their exposure to HIV is *confidential*; partners are not told who reported their name or when the reported exposure occurred. As well, information about partners is not reported back to the original HIV-infected person. It is *voluntary*; the infected person decides which names, if any, to reveal to the interviewer.

PCRS can be an effective tool for reaching persons at very high risk for HIV infection: in studies of HIV PCRS, 8%-39% of partners tested were found to have previously undiagnosed HIV infection.⁵ However, a recent survey of health departments in U.S. areas with high reported rates of HIV found that, in areas with mandatory HIV reporting, only 52% of persons infected with HIV were interviewed for PCRS.⁶ Acceptability of PCRS has been indicated in surveys of individuals seeking HIV testing, HIV-infected persons, and notified partners.^{7,8,9} PCRS has been found to be cost-effective.^{10,11,12}

CORE ELEMENTS, KEY CHARACTERISTICS, AND PROCEDURES

Core Elements are those components that are critical features of an intervention's intent and design and that are thought to be responsible for its effectiveness and that consequently must be maintained without alteration to ensure program effectiveness. Core elements are derived from the behavioral theory upon which it the intervention is based. They are essential to the implementation of the program and cannot be ignored, added to, or changed. PCRS has 6 core elements which include:

- 1) All services are both voluntary and confidential.
- 2) Identifying and contacting all persons with HIV (index or original clients) to offer them PCRS. These may be persons with newly diagnosed HIV or persons with previously diagnosed HIV who have ongoing risky sexual and injection-drug-use behaviors.
- 3) Interviewing index clients who accept PCRS to elicit names of and locating information for sex and injection-drug-paraphernalia-sharing partners.
- 4) Locating named partners, notifying them of their exposure to HIV, providing HIV prevention counseling to them, and recommending HIV testing.
- 5) Providing HIV counseling and testing to partners and ensuring they receive their test results.
- 6) Linking partners, especially those who test positive, to appropriate medical evaluation, treatment, prevention, and other services.

Key Characteristics are crucial activities and delivery methods for conducting an intervention, which may be tailored for different agencies and at-risk populations. These characteristics, however, can be adapted or tailored to meet the needs of the target population and ensure cultural appropriateness of the strategy. PCRS has 4 key characteristics:

- May be delivered through provider-referral, whereby the PCRS worker locates and informs sex or injection-drug-paraphernalia-sharing partners of their exposure; and/or through client-referral, whereby the infected person takes responsibility for informing his or her partners. Sometimes a combination of these approaches either contract-referral or dual-referral (see p.65 for definitions) is used. Provider referral has been shown to be more effective than client referral.
- Is delivered in a continuum of care that includes the capacity to refer or test sex and injection-drug-paraphernalia-sharing partners to HIV counseling, testing, and treatment, as well as to other services (e.g., STD treatment, family planning, violence prevention, drug treatment, social support, housing).
- May reduce behavioral risks for acquiring or transmitting HIV infection by providing client-centered counseling for HIV-infected individuals and their partners. In addition, client-centered counseling will help the provider understand the readiness of the client to

- notify partners. This will allow the provider to offer services to assist the client in successfully notifying partners without adverse consequence.
- Should not be a one-time service. It should be offered as soon as an HIV-infected individual learns his or her serostatus and made available throughout that person's counseling and treatment. If new partners are exposed in the future, PCRS should be made available again. HIV-infected individuals should have the ability to access PCRS whenever needed.

<u>Procedures</u> describe the activities that make up the content of the intervention and provide direction to agencies or organizations regarding the implementation of the intervention. Procedures for PCRS follow.

PCRS activities are science-based and require knowledge, skills, and training. It is part of a complex array of services needed by PLWH, which begins when a person tests HIV-positive and continues after the client enters care.

PCRS is usually done by health departments; therefore, a community-based organization (CBO) planning to provide any or all services of PCRS should collaborate closely with its state or local health department to avoid duplication of services and ensure that all CBO procedures are consistent with health department policies and procedures. A written agreement with the state or local health department outlining the roles and responsibilities of the CBO and the health department should be in place before a CBO implements PCRS. In some jurisdictions, state or local laws and regulations limit or prohibit PCRS being done outside the health department.

PCRS is not complete without each of its 6 core elements. Therefore, CBOs planning to provide PCRS must either fully address all elements, or, if this is not possible, maintain formal written agreements with other agencies, organizations, or providers that will deliver the other elements. In addition, because most HIV diagnoses are made by private medical providers, CBOs should consider working with private providers as well as with other agencies and organizations involved in the care of PLWH to improve understanding of the value of PCRS and to integrate PCRS into their other services. At a minimum, CBOs providing PCRS should ensure that information about their services is easily accessible by health care providers in the public and private sectors and other agencies and organizations diagnosing or providing services to PLWH.

Two major sources of recruitment for PCRS include health care providers who report HIV cases to the health department according to state regulations and counseling, testing, and referral sites. Agencies can assist with referral into PCRS by helping health care providers understand the benefits to PCRS and by ensuring that all positive HIV test result counseling sessions at counseling and testing sites include referral to PCRS.

Interviewing index clients who accept PCRS serves several functions including, providing client-centered HIV prevention counseling and information to the index client, assessing the index client's need for other services and making appropriate referrals, and eliciting names of and locating information on sex and injection-drug-paraphernalia-sharing partners or children or infants who may have been exposed perinatally or through breast feeding. During the interview, the PCRS provider should also establish a plan for notifying partners (see below for notification

strategies) and if appropriate arranging for follow-up to determine if contact was made. PCRS should be an ongoing process for clients who have new sex or injection-drug-paraphernalia-sharing partners; therefore, clients who remain sexually active or continue to use injection drugs should be counseled regarding self-disclosure of HIV status and provided opportunities to develop their disclosure skills.

PCRS programs should have explicit procedures regarding partner elicitation, including, but not limited to:

- Determining the interview period (i.e., how long before the index client's diagnosis to attempt to identify partners)
- Following special considerations related to spouses (e.g., federal legislation and related state laws and regulations requiring that a good-faith effort be made in notifying spouses), including establishing an approach to clients who will not give consent and will not allow the provider to notify current or past marriage partner(s)
- Establishing an approach to clients who decline to disclose partner names
- Explaining to index clients all available options for notifying their partners (e.g., client-, provider-, contract-, or dual-referral), including advantages and disadvantages of each
- Assessing and addressing potential for partner violence. PCRS workers should be aware
 of the potential for partner violence and be prepared to make appropriate referrals. If the
 provider has an indication of a potentially violent situation for the client or others, the
 provider must make an assessment prior to notifying the partner, seek expert consultation
 before proceeding, and comply with relevant state laws and local regulations
- Formulating plans for notifying partners of their exposure including if, how, and when specific partners will be informed of their risk of exposure

Locating and notifying named partners should begin as soon as possible after the diagnosis of HIV in the index patient. Partners should be informed of their possible exposure to HIV; provided with accurate information about transmission and prevention of HIV; informed of the benefit of knowing one's status; assisted in accessing counseling, testing, and referral services; and cautioned about the possible negative consequences of disclosure of one's own or another's HIV status.

There are three main strategies for reaching and informing partners of their exposure. PCRS workers should assist clients in determining the best strategy for notifying each partner named.

- <u>Provider-Referral</u> the clinical care provider, health department staff, or other PCRS provider, with permission from the HIV-infected client, informs the partner(s) and refers him or her to counseling, testing, and other support services. Although some clinicians may wish to take on the responsibility for informing partners, one observational study suggested that health department specialists were more successful than physicians in interviewing patients and locating partners.¹³
- Patient- or Client-Referral the HIV-infected person accepts full responsibility for informing his or her partners of their possible exposure to HIV and for referring them to HIV counseling and testing services. Clients should receive information and coaching regarding the best way to inform their partners, dealing with the psychological and social

impact of HIV status disclosure, dealing with partner reactions (including violence), and on how and where partners can access counseling and testing. Although some persons initially prefer to inform their partners themselves, many clients often find this more difficult than anticipated. Furthermore, results from a randomized trial showed that notification by health department staff was substantially more effective than notification by the infected person.¹⁴

- <u>Combined Referral</u> two strategies of combined referral provide variations on provider- and client-referral strategies by including elements of both.
 - o *Contract-referral*, the infected person has a specified number of days to notify his or her partners. If, by the contract date, the partners have not come for counseling and testing, they are contacted by the PCRS provider.
 - O *Dual-referral*, the HIV-infected client and the provider inform the partner together. Some reports of partner violence after notification suggest a need for caution, but violence seems to be rare. 15,16

Many states and some cities or localities have laws and regulations about informing partners of their exposure to HIV. Some health departments require that even if a client declines to report a partner, the PCRS provider must report to the health department any partner of whom he or she is aware. Some states also have laws requiring disclosure by providers to third parties known to be at significant risk for future HIV transmission from clients known to be infected. This is called duty to warn. ¹⁷ Agencies or organizations that choose to implement PCRS should familiarize themselves with local, state, and federal regulations governing informing partners of potential exposure as well as potential duty to warn. Finally, the Ryan White CARE Reauthorization Act requires that health departments receiving Ryan White funds show good faith efforts to notify marriage partners of HIV-infected persons.

All partners notified should receive appropriate client-centered counseling and be offered anonymous or confidential testing (if not already known to be positive) and referral services. Testing may be done at the time of notification (rapid testing (RT) and non-blood specimen collection options can facilitate this type of testing) or may be accomplished by escorting or referring the partner to a counseling and testing site. For partners who choose non-RT methods, detailed locating information should be obtained to ensure that results are given, and for those partners referred, follow-up should be arranged to ensure that counseling and testing were provided. Regardless of how testing is accomplished, all aspects of counseling and testing should follow CDC's guidelines¹⁸ and must be in accordance with federal, state, and local laws, regulations, and policies, including the Clinical Laboratory Improvement Amendment (CLIA). PCRS workers should also maintain referral agreements and up-to-date resource guides to provide appropriate referrals. For partners who test positive, linking them to appropriate medical care and prevention services is essential. For partners who are HIV-negative referrals for prevention services should be made.

Because PCRS may place a substantial burden on resources, CBO program managers may need to develop policies for prioritizing PCRS activities, such as the order in which PLWH are offered PCRS or the order in which partners are located and offered counseling, testing and referral and PCRS. The PCRS Guidance ¹⁸ suggests the following be considered when prioritizing efforts:

- The partner who is most likely to transmit HIV to others should receive the highest priority.
- Partners of a recently infected client who had contact in the prior 6 months are most likely to have been exposed and should be considered high priority.
- Partners who are unlikely to be aware of their exposure to HIV should be considered high priority.
- Current partners are considered a high priority because they may be at continued risk for infection.
- Partners with a history of other STDs are high priority.
- Partners of clients with resistant strains of HIV should be considered high priority.

RESOURCE REQUIREMENTS

PCRS services include three phases: working the HIV infected client, locating partners, and notifying partners of their potential exposure and providing additional services. These may all be performed by the same person within an agency, or may be divided between two or more individuals depending on the needs of the agency and the skill level of the staff. If an agency provides CTR services, elicitation may be included within counseling for clients who test positive for HIV, although agencies should be aware that including elicitation within the counseling session will increase significantly the amount of time required for counseling. This service may also be conducted at a later time if the client is not ready to provide this information immediately or if elicitation of partners does not fit within the logistics of the CTR service, however, the success of PCRS as a prevention strategy may be diminished if newly diagnosed clients are lost to follow up at a later time. Locating and notifying partners may require a greater time commitment from the PCRS worker depending on the number of partners elicited, the extent and accuracy of the locating information provided, whether counseling and testing will be provided on site, and on the type of referrals that the client wishes to pursue. Finally, accurate records must be maintained to ensure that all clients are reached and partners are notified and provided with appropriate referrals for CTR (or are provided CTR if the agency providing PCRS is equipped to offer this service) or other services as needed and that services are coordinated with the state or local health department. Staffing levels for PCRS will vary according to the design of the program (all workers performing all components versus division of the components between workers) and the number of clients expected to be served. In general, agencies could expect to serve up to 5-7 new clients per week for each 1.0 full-time equivalent (FTE) PCRS provider on staff. In addition, a 1.0 FTE supervisor (per 5-7 PCRS providers) will be required to oversee staff, maintain records, and work with the state or local health department to coordinate delivery of services.

RECRUITMENT

CBOs planning to provide PCRS should have clearly defined strategies for *identifying* potential index clients. All persons with newly diagnosed HIV are candidates for PCRS. Some examples of other persons who are candidates for PCRS include: HIV-infected persons who in the past were not offered PCRS, persons with previously diagnosed HIV infection who are now seeking

STD or family planning services, and persons who in the past declined or only partially participated in PCRS but have now decided to participate fully. Potential index clients may be identified from among persons already served by the CBO or may be identified by other agencies, organizations, or providers and referred to the CBO for PCRS. CBOs accepting referrals for PCRS from other agencies, organizations, or providers should do so only under a formal, written agreement (e.g., memorandum of agreement, contract) that clearly describes the roles and responsibilities of each party. Such agreements should be reviewed and approved by the health department and should ensure that appropriate consents for release of information have been signed by the referred client to allow exchange of necessary information between the CBO and the referring entity.

CBOs providing PCRS should have explicit procedures regarding contacting potential index clients and offering them PCRS, including, but not limited to, the following:

- How to contact them (e.g., in person, by telephone, by mail)
- What steps to take before contacting them (e.g., for persons with newly diagnosed HIV, ensuring that the diagnosing person or organization knows of, and agrees with, the CBO's plan to contact their client for PCRS)
- When to contact them (i.e., the intervals between identifying the client, initiating contact, and establishing contact)
- What to do and say when contacting them
- What to do if unable to locate them or if they decline PCRS when it is offered (e.g., notifying the health department of the situation)

Index clients should be offered PCRS at the earliest possible opportunity. However, for persons newly diagnosed with HIV, reactions to learning they are infected will vary and personal circumstances will differ. PCRS workers should recognize and accommodate clients who need to resolve other issues before being ready to participate in PCRS. CBOs providing PCRS should have clear guidelines for these situations to avoid inappropriate delays.

Agencies or organizations wishing to provide PCRS should review the Procedural Guidance for Recruitment (see p. 7) to determine if there are any additional recruitment strategies which might be appropriate for their target population.

PHYSICAL SETTING CHARACTERISTICS

The CBO's office or clinic provides the safest and most convenient setting in which to interview and counsel clients. This setting allows for greater control over the interview process and permits access to additional personnel and materials, including medical records. However, interviews conducted outside the office or clinic setting, in surroundings in which clients feel more comfortable, may facilitate the process. Interviews conducted in the home, for example, may afford the client ready access to information (e.g., personal address books, pictures) that can be helpful in locating partners. Interviews undertaken outside the clinic or office setting (e.g., crack houses, bars, housing projects, cars) introduce the issue of personal safety for staff, which must be taken into consideration. Regardless of where PCRS is done, confidentiality and privacy must be ensured.

When efforts to meet with a client in person have been unsuccessful or when the client is not in the same city as the PCRS worker, a telephone interview may be considered, if consistent with local policy. Telephone interviews do not allow client observation and should be used with discretion and in accordance with CDC's guidelines¹⁸ and state and local policies and procedures. When interviewing by phone, certain privacy issues must be taken into account (e.g., making sure one is speaking to the client, cellular phones are not being used, no one else is on the line).

Notification of partners should take place at the time and place that is most convenient to the partner while still assuring confidentiality of the partner being notified. In-person notification should be used wherever possible. Notification by mail may be acceptable in certain circumstances, but should always be followed by personal contact. If an agency is providing rapid testing with its PCRS services, the location should take into account the demands of this situation. Outside referrals for counseling and testing should be made in accordance with appropriate referral policies and followed up to ensure that the referral was completed.

NECESSARY POLICIES AND STANDARDS

Before an agency attempts to deliver Partner Counseling and Referral Services, the following policies and procedures should be in place to protect participants, the agency, and the PCRS provider:

<u>Confidential and Voluntary:</u> A system must be in place to ensure that confidentiality is maintained for all participants in the program. Before sharing any information with another agency to which a client is referred, signed informed consent from a client or his/her legal guardian must be obtained. In addition, persons testing anonymously must not be required to disclose their identity in order to receive PCRS. Finally, participation in PCRS is always voluntary, and PCRS providers should ensure that clients are aware of their right to refuse or delay their participation in PCRS.

Informed Consent: All clients tested at CDC-funded testing sites should be informed of the availability of PCRS services at the earliest opportunity. Agencies must have a consent form which carefully and clearly explains in easily understandable language the agency's responsibility and the participants' rights as well as options for serving partners. Individual state laws apply to consent procedures for minors, but at a minimum, consent should be obtained from each participant and/or a legal guardian if the participant is a minor or unable to give legal consent. For anonymous clients a signature is not required, but documentation that client rights were explained must be maintained in client records.

<u>Cultural Competence:</u> Agencies must strive to offer culturally competent service by being aware of the demographic, cultural, and epidemiological profile of their communities. Agencies should hire, promote, and train staff across all disciplines to be representative of and sensitive to these cultures. In addition, materials and services must be offered in the preferred language of clients/consumers where possible, or translation should be available if appropriate. Finally, agencies should facilitate community and client/consumer involvement in designing and

implementing prevention services to ensure that important cultural issues are incorporated. The Office of Minority Health of the Department of Health and Human Services has published the *National Standards for Culturally and Linguistically Appropriate Services in Health Care* which should be used as a guide for ensuring cultural competency in programs and services. Please see the Cultural Competence section in the introduction of this document (page 9) for standards for developing culturally and linguistically competent programs and services.

<u>Legal/Ethical Policies:</u> It is important to keep in mind that PCRS is an intervention that deals with disclosure of HIV status, and PCRS workers must review with the client the legal and ethical reasons for informing partners. With that in mind, agencies must know their state laws regarding disclosure of HIV status to sexual and/or needle-sharing partners, and agencies are obligated to inform participants of the potential duty to warn and the agency's responsibility, especially in the case of a spouse. PCRS workers should help the HIV-positive client to prioritize partners to be notified based on the likelihood of past or future transmission. Agencies also must inform participants about state laws regarding the reporting of domestic violence, child abuse, sexual abuse of minors, and elder abuse.

<u>Data Security:</u> Collect and report data consistent with CDC requirements to ensure data security and client confidentiality.

Referrals: Agencies must be prepared to supply appropriate referrals to clients and partners, as necessary. Providers must know about referral sources for care, counseling and testing, and prevention interventions (Prevention Case Management, Health Department/Community-based Organization programs for prevention interventions with PLWH) if consumers need additional assistance in decreasing risk behavior.

QUALITY ASSURANCE

Training is critical for successful PCRS. Training for PCRS workers is provided by CDC and includes:

- 1) Initial training plus periodic updates on standards, objectives, and specific guidelines for PCRS.
- 2) Knowledge of HIV infection, transmission, and treatment.
- 3) Cultural competence in eliciting information on partners.
- 4) Client-centered counseling.
- 5) Protecting individuals' rights to privacy.
- 6) How to use scientific information in prioritizing partners.
- 7) How to administer HIV tests when appropriate.

- 8) How to defuse potentially violent situations involving clients, partners, or staff.
- 9) Understanding local, state, and federal laws regarding PCRS as well as health care issues including the right to privacy and confidentiality.

Quality assurance methods including written job descriptions, periodic direct observation of PCRS workers, peer review of selected cases, and consumer satisfaction surveys should be in place to ensure that appropriate standardized methods are used for:

- 1) Counseling HIV-infected clients regarding the notification of their partners.
- 2) Developing a PCRS plan with HIV-infected clients.
- 3) Prioritizing which partners are to be reached.
- 4) Locating and informing those partners of their possible exposure to HIV.
- 5) Providing immediate counseling and testing services to informed partners and/or referring them to other service providers.
- 6) Collecting, analyzing, using, and storing PCRS data.

MONITORING AND EVALUATION

Evaluation and monitoring of recruitment activities include the following:

- Collect and report client-level data.
- Collect and report standardized process and outcome monitoring data consistent with CDC requirements.
- Use of the CDC developed PEMS (Program Evaluation Monitoring System) to report date electronically. Organizations may use, under certain circumstances, a local system provided it meets required system specifications.
- Collect and report data consistent with CDC's requirements to ensure data quality and security and client confidentiality.
- Collaborate with CDC in assessing the impact of HIV prevention activities by participating in special projects upon request.
- Collect and report data on the following indicators:
 - o **III.D-** Percent of contacts with unknown or negative serostatus receiving an HIV test after PCRS notification.
 - o **III.E-** Percent of contacts with a newly identified, confirmed HIV-positive test among contacts who are tested.
 - o **III.F-** Percent of contacts with a known, confirmed HIV-positive test among all contacts.

- o **IV.A-** Proportion of client records with the CDC-required demographic and behavioral risk information
- O V.A The mean number of outreach contacts required to get a person (living with HIV, their sex partners and injection drug-using contacts or at very high risk for HIV infection) to access referrals made under this program announcement.

KEY ARTICLES AND RESOURCES

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